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Barriers to and facilitators of end-of-life decision-making by neonatologists and neonatal nurses in neonates: a qualitative study.

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Abstract

Context Making end-of-life decisions in neonates involves ethically difficult and distressing dilemmas for healthcare providers. Insight into which factors complicate or facilitate this decision-making process could be a necessary first step in formulating recommendations to aid future practice.

Objectives This study aimed to identify barriers to and facilitators of the end-of-life decision-making process as perceived by neonatologists and nurses.

Methods We conducted semi-structured face-to-face interviews with 15 neonatologists and 15 neonatal nurses, recruited through four neonatal intensive care units in Flanders, Belgium. They were asked what factors had facilitated and complicated previous end-of-life decision-making processes. Two researchers independently analysed the data, using thematic content analysis to extract and summarize barriers and facilitators.

Results Barriers and facilitators were found at three distinct levels: the case-specific context (e.g. uncertainty of the diagnosis and specific characteristics of the child, the parents and the healthcare providers which make decision-making more difficult), the decision-making process (e.g. multidisciplinary consultations and advance care planning (ACP) which make decision-making easier), and the overarching structure (e.g. lack of privacy and complex legislation making decision-making more challenging).

Conclusions Barriers and facilitators found in this study can lead to recommendations, some simpler to implement than others, to aid the complex end-of-life decision making process. Recommendations include establishing regular multidisciplinary meetings to include all healthcare providers and reduce unnecessary uncertainty, routinely implementing ACP in severely ill neonates to make important decisions beforehand, creating privacy for bad-news conversations with parents and reviewing the complex legal framework of perinatal end-of-life decision-making.

Keywords:

Perinatal death; End of Life Care; Decision Making; Qualitative Research; Barriers and Facilitators; Intensive Care Units, Neonatal

Key message:

Barriers and facilitators of end-of-life decision-making in neonates indicated by healthcare providers can be divided into three levels, the case-specific context, the decision-making process and the overarching structure. Key themes include uncertainty of the diagnosis; characteristics of the child, parents or healthcare providers; lack of privacy and difficult legal frameworks.

Running title:

What influences neonatal end-of-life decisions

Availability of data and material:

Transcripts, codebooks and detailed research protocols are available upon written request to the corresponding author (Laure.Dombrecht@UGent.be).

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1 Introduction

2 Despite medical advances over the last decades, a substantial number of children die before
3 they reach the age of one(1–3). Many of these deaths are preceded by an end-of-life decision
4 (ELD) with a potentially life-shortening effect, such as withholding or withdrawing
5 medication or actively ending life with lethal medication(4–7). The medical and ethical
6 dilemmas during end-of-life (EoL) decision-making cause significant distress in
7 neonatologists, nurses and parents(8). In most countries, including in Belgium, actively
8 ending life with lethal medication is illegal, though previous research shows that some
9 healthcare providers would consider actively ending life acceptable in severe or lethal
10 cases(9), and that it does happen in clinical practice(3,10). This might make the decision-
11 making process even more difficult. Therefore, research into what could make this process
12 less distressing is imperative.

13 Both healthcare providers and parents play an active role in EoL decision-making(11).
14 However, healthcare providers have a range of EoL experiences which makes them ideally
15 placed to reflect on what makes such decision-making easier or more difficult, whereas
16 parents usually have only the one uniquely personal and tragic experience. Since the
17 viewpoint of parents is fundamentally different from that of healthcare providers, but still
18 crucial to neonatal EoL decision-making, a forthcoming paper will focus solely on their
19 experiences. From a healthcare provider perspective, physicians are experts in understanding
20 the prognosis and possible outcomes(12), while nurses are continually present at the bedside
21 and often have a closer personal bond with the parents, making them key figures in building a
22 trusting relationship with the parents(13,14) which is crucial in EoL decision-making. They
23 thus have a unique and important role in the decision-making process, making investigation
24 of both viewpoints essential.

25 To our knowledge, no studies exist that describe barriers to and facilitators of ELDs in
26 neonates from a healthcare provider perspective. However, previous studies with a broader
27 focus on aspects of ELDs in neonates mention factors influencing decision-making: 1) a
28 French interview study on attitudes and ELD practices revealed that nurses often experience
29 the time between grasping the severity of the situation and actually taking a decision as
30 extremely difficult as they are constantly confronted with suffering of the child(13); 2) a
31 recent online survey in neonatologists and nurses in Switzerland on decision-making at the
32 limit of viability identified several crucial difficulties such as prognostic uncertainty,
33 difficulties in interpreting the attitude of the parents, insufficient time for decision-making,
34 legal constraints and conflicts between their own principles and unit policy(12).

35 Furthermore, factors influencing decision-making are mentioned in studies examining overall
36 EoL care in neonates. In one study on EoL experiences, physicians indicated that a bond of
37 trust with parents makes communicating bad news easier(8); another, on moral obligations
38 experienced by healthcare providers, reveals that an uncertain prognosis and ambivalence
39 about including parents while wanting to shield them from the burden of decision-making are
40 key difficulties(15).

41 These studies revealed some influencing factors on EoL decision-making in neonates, but did
42 not explicitly focus on barriers and facilitators, making it possible that key factors may have
43 been overlooked. We therefore examine barriers and facilitators in the EoL decision-making
44 process in neonates, as experienced by neonatologists and nurses. Hereby, we focused on
45 what makes it easier or more difficult in the process to come to or to make the end-of-life
46 decision. We aimed to study these barriers and facilitators, in the expectation that insight into
47 them can usefully shape future EoL decision-making.

48 Methods

Study design

A qualitative study was conducted using semi-structured face-to-face interviews with neonatologists and neonatal nurses working in a Flemish neonatal intensive care unit (NICU). We chose a qualitative research methodology to cover the complexity, subtlety and individual specificity of experiences in the end-of-life decision-making process regarding neonates that would be missed by a quantitative approach. Because of the sensitivity of the subject we opted for individual interviews. Criteria for reporting qualitative research from the COREQ guidelines were used(16) (see Table 1 in appendix).

Setting and participants

We recruited neonatologists working as resident physicians at one of four Flemish NICUs (University hospitals of Ghent, Brussels and Leuven, and general hospital Sint-Jan Bruges) between December 2017 and July 2018 who had been the attending/treating physician to at least one child who had died at the NICU where an ELD was made in the past year, and nurses who had been the most involved. No exclusion criteria were used.

Recruitment

A neonatologist of each participating hospital (FC, LG, GN and LC) informed all neonatologists and nurses within their respective NICU of the purpose of the study, and provided contact details of those willing to participate. Researchers contacted them and set up a date for the interview either at their NICU or at their home residency. Purposeful sampling was used to select participants.

Data collection

A topic guide (Box 1) was developed by a multidisciplinary team of nine experienced researchers in the fields of end-of-life care and neonatology. Participants were asked what made it easier or more difficult to make ELDs in the NICU. Before the interview, a short questionnaire was administered to collect socio-demographic data. LDm (female, MSc in experimental psychology; Doctoral Researcher) and VP (female, MA in neurolinguistics and BSc in psychology; Doctoral Researcher) performed all interviews with the participants. Data were collected until no new barriers and facilitators emerged for both neonatologists and nurses separately, and data saturation was achieved.

Data analysis

Interviews were audiotaped and transcribed verbatim. NVivo 12 was used for structuring the data and thematic content analysis(17) was used to analyse it. Two researchers coded the interviews independently and openly by means of inductive coding during which they searched for facilitators and barriers that influenced the end-of-life decision-making process. The first eight interviews were coded by both researchers. After five interviews a first discussion on code nodes and trees occurred. The other 22 interviews were coded by one of the researchers. Code nodes and trees were discussed amongst both researchers at regular meetings, and during two separate meetings afterwards with all co-authors. When coding discrepancies occurred, consensus was sought. Data saturation was reached when no new codes emerged for three consecutive interviews in neonatologists and nurses separately, and when a similar number of participants from each participating hospital were recruited. The final model of factors influencing EoL decision-making in neonates was agreed upon by all authors.

Results

We conducted 15 interviews with neonatologists and 15 with neonatal nurses from four NICUs (Table 1), lasting about an hour each. Identified themes regarding barriers and facilitators on the EoL decision-making process were classified into three discrete levels: 1) context level, themes related to the specific EoL case; 2) process level, themes related to

characteristics of the decision-making process itself; and 3) structure level, themes related to characteristics of the overarching determinants of overall policy and practice in the NICU ward or in the wider society (Table 2).

Context level

According to the interviewees, the characteristics of key players such as the child, parents and healthcare providers can have an influence on the decision-making process.

Child characteristics

Physicians and nurses mentioned the influence of several child characteristics on the decision-making process including gestational age, prognosis and possible ELD options.

When the child is born at full term, healthcare providers indicated that the decision to transition from curative care to an ELD is more difficult because a healthy, full term baby had a high chance of survival early on, while the survival chances of an extremely premature baby were already lower making everyone prepared for bad news.

"It turns out that I find it more difficult with children born at term than with a 24-25 week baby. With the latter I feel like, let's give it a chance but then nature decides that it won't work. That's different to children who are doing really well up to 38 weeks in the womb, and then they are born and get serious infections. If they had been delivered by caesarean a week earlier, you'd have a perfect child. With a premature baby there's so little you can do when labour starts." - Nurse 12

Both neonatologists and nurses indicate that decisions are easier to make when a bad prognosis becomes evident quickly and is certain, while fluctuations in health lead to doubts about life-expectancy and/or future quality of life.

"It often has to do with pathology, and you know the type of discussion you can have about 'how certain is your prognosis?' That's especially the case with premature babies with extensive brain haemorrhages. I find it easy if they have already been fairly intensively treated and you notice that, well, it's not really working. And then there's a brain haemorrhage on top of all the rest. Then you think, right, well, this really doesn't look good. But, well, if you hear the figures, and they mainly have to do with extremely premature babies, at 25 or 26 weeks, there is quite a lot of debate about that. [...] that does lead to quite a difference in opinions." - Doctor 2

Lastly, of the interviewees, only neonatologists discuss the importance of being sure that all options have been explored first, before an ELD is considered. When all curative options failed, and an ELD is the only way to ensure an end to the suffering of the child, the decision is described as being easier than when other treatment options are still possible. Furthermore, when an EoL decision is made, physicians indicate that it is easier if withholding or withdrawing treatment is sufficient rather than when the only possible option involves actively ending life with lethal medication.

Parent characteristics

Neonatologists and nurses indicate the same barriers and facilitators in terms of parent characteristics, including cultural and language differences, socio-economic status and therapeutic relationships with parents.

In general, healthcare providers indicate that EoL decision-making is easier when parents have the same culture and language as the physicians and nurses involved. Translations make healthcare providers feel less able to convey the depth and nuances needed to describe the diagnoses and (EoL) treatment options. A difference in cultural background

between healthcare providers and parents makes neonatologists and nurses feel they are limited to only discussing certain ELDs.

“... a very difficult context is for example parents with a Muslim background, who want everything to be done for their child no matter the cost, even though there is no possibility of doing anything useful. And you still have to continue on, that you have to do a futile medical act. That makes it more difficult.” – Doctor 11

A lower socio-economic status was also indicated as an important influencing factor. When a child will suffer a severe handicap in future, and it is judged that parents will not be able to provide a safe environment for the child financially or emotionally, healthcare practitioners find deciding on an ELD easier than when the child will be cared for and both parents are well-resourced financially and emotionally. The former include unstable household situations with e.g. drug abuse, criminal history, teenage pregnancies and extreme debt. The healthcare providers indicate they find these unstable situations facilitate end-of-life decision-making because they take into consideration the extreme suffering of the child in future, due to their medical condition, combined with a difficult family life. While some participants struggled with the fact that socio-economic status was indicated as an influencing factor, reflection on the ethical ramifications, others stated it as a matter of fact and rationalized this as one of many influencing factors in decision-making.

Lastly, both neonatologists and nurses indicate that the EoL decision-making process is easier when a therapeutic relationship is established with the parents.

Healthcare provider characteristics

Previous experience with EoL decisions was mentioned as a factor in making the EoL decision-making process easier, because healthcare providers are better able to anticipate the child's future condition. Furthermore, some nurses indicated that experience with the disability and suffering of treated children later in their lives makes EoL decision-making easier, because they were better able to envisage the child's future quality of life.

“I think experience does help... certainly in the learning process surrounding end-of-life decisions. If I think back now to about 14 years ago, the first time I cared for a family with a dying child, well, you still really don't know what you are supposed to ask parents, or suggest to them. And now I really have done quite a lot and then you do end up learning.” - Nurse 5

Lastly, physicians and nurses mentioned the effect of their own ability to relate to the specific case; when they have children of their own or their family situation is similar, deciding on an ELD is more difficult.

Process level

According to neonatologists and nurses the communication between all involved actors (parents, neonatologists, nurses, psychologists, etc.), divergence of opinion and advance care planning are key elements.

Communication and multidisciplinary consultations

Healthcare providers mentioned that communication amongst all actors, debriefings after death and formal second opinions are crucial factors during EoL decision-making in neonates.

Intense communication between healthcare providers and parents is imperative in making ELDs. All actors should be aware of the most recent updates on the child, and of each other's views and opinions.

1 *“When communication goes badly, I think that those cases are the most difficult. I am*
 2 *thinking about a child that was ill for a long time [...] what the parents wished and*
 3 *how the physician interpreted this did not match.” – Nurse 5*

4 Healthcare practitioners also mentioned communication between practitioners both inside
 5 and beyond the team as helpful during the decision-making process, either formally
 6 during multidisciplinary team meetings or debriefings, or informally. Multidisciplinary
 7 meetings with the entire team, including physicians and nurses, ensures that decisions are
 8 supported by all and that everyone is included in the decision-making process. When
 9 neonatologists, or more frequently nurses, are excluded from this decision-making
 10 process, but are later required to implement the decision, the EoL decision-making
 11 process was experienced as being harder.

12 *“I wasn’t involved then, actually, and then it was difficult at that point, if the*
 13 *decisions have already been made, well, to go back on them. As an outsider, you*
 14 *might say, although of course we had discussed it with each other beforehand. But*
 15 *how it actually happened. And if the child has died, then you think oh dear, we do*
 16 *need to sit down with everyone as soon as possible and discuss it and to see what we*
 17 *need to do differently next time.” - Doctor 1*

18 Only neonatologists expressed the importance of asking for a formal second opinion by
 19 an independent physician either within their own hospital (e.g. other disciplines such as
 20 cardiology) or from another hospital.

21 *“...then I think the second opinion system is a good system. If we have a situation like*
 22 *that, I phone (name) and I say: (name) we are going to refer that child through, give*
 23 *me a fresh opinion.” - Doctor 3*

24 Formal and preset debriefings amongst healthcare providers after a child died were
 25 indicated as helpful in future EoL decision-making processes. Debriefings provide
 26 reflection on what went well and what could be improved while an absence of debriefings
 27 can leave other members of the medical team with unresolved questions.

28 ***Divergence of opinion***

29 When one of the involved actors (parents, nurses, neonatologists) wants to continue
 30 curative treatment and others opt for an ELD, compromises need to be made. Differing
 31 opinions can put pressure on any one of them to change their minds, making EoL
 32 decision-making extremely difficult.

33 *“If I’m not on the same wavelength as the parents, that makes it difficult for me. So it*
 34 *can go two ways. If the parents ask to stop (the treatment), but I’m not yet ready for*
 35 *that myself or I think it isn’t clear enough yet. Those are the things that make it*
 36 *difficult. If I believe that there is no point, and the parents don’t agree, I find that*
 37 *difficult too.” - Doctor 2*

38 ***Advance care planning (ACP)/ mapping of possible actions***

39 According to neonatologists and nurses, ACP is a crucial factor in EoL decision-making.
 40 Considering in advance together with healthcare providers and parents all the directions
 41 the child’s condition can take and deciding on which medical responses will be made in
 42 each leads to easier decision-making than when rushed decisions have to be made due to
 43 acute deterioration where ACP did not or could not take place.

44 *“... the parents can already indicate directly at that point that, yes but doctor, if my*
 45 *child is born at 24 weeks and you are talking about haemorrhages that can happen, if*
 46 *that is the case, I want to be certain you won’t intervene. Or otherwise I want, if it*

turns out that you expect my child will have certain disabilities in the future, I don't want that. In the theoretical situation, then, that makes it easy to go back afterwards, when what you discussed actually happens and that you have already discussed it with the parents yourself." - Doctor 7

When an ELD is discussed during the ACP process, the dying process can be planned according to the wishes of parents and the advice of the healthcare providers. Planning includes reserving a private room, making sure the parents are present, that death is not rushed, and creating memories with parents.

"I remember a case where the death was fairly sudden, in a reanimation setting, and the door <of the consultation room> was open. And the nurses for the other children didn't really realise that the child was dying and the father said: one image still sticks in my mind: that is those laughing nurses walking past the desk. And that was very difficult for him and I also reported that back to the nurses here, and they decided to put a lamp on the desk and to use that, actually, as a signal that serenity was needed." - Doctor 11

Structure level

A third important level includes factors relating to the overarching structure of the ward, the hospital and the broader society that could make decision-making and the decision-making process easier or more difficult.

Emotional and practical support at the ward

According to healthcare providers, emotional support (or lack thereof) from colleagues is a crucial facilitator (or barrier) in EoL decision-making in neonates. This includes being 'a shoulder to cry on' and being a person to confirm diagnoses or treatment options with. Most neonatologists and nurses mentioned the lack of psychological support for team members at the NICU.

"I think that we need a psychologist, well we have a psychologist at the ward. She is there for the parents and I think that she could mean much more to our ward. [...] She <the psychologist> is not there for us, and we see that, that she's not there for us." - Nurse 1

Participants indicate the positive effect of a ward that promotes collegiality and teamwork culture during EoL care. When other nurses can take over some of your daily tasks or aid in caring for less critical patients, or physicians can cover for each other so that they have the time to allocate solely to the parents, EoL care for a dying neonate is indicated to be easier.

"If my other children are taken over by colleagues, so I only have to concern myself with that baby. In terms of the team, if it really starts to be a critical time, not yet leading up to but if they are still stable but if the parents are there then, for example, then I could just concentrate on those people quietly on my own. My colleagues would take over my work, in fact. That is very practical but very important." - Nurse 1

NICU policy, practice and expertise

Healthcare providers mentioned the negative effect of lack of a separate room for privacy, shortage of available trained personnel and differences in expertise across NICUs.

"This is the only interview room we have for everyone, for everything, for whoever it is. To talk about going home, release from hospital, follow-up conversations with nurses, trainees. It all happens here. And people just wander in and out. That isn't very pleasant, you just want to be alone with the parents at that point and concentrate

on them. Leave your phone with someone else so that you can devote all your attention to those people and that story.” - Doctor 14

Another important aspect of NICU practice mentioned by both healthcare providers is that a shortage of neonatologists and nurses experienced in EoL care leads to a higher burden on qualified staff.

Only neonatologists mentioned that differences in knowledge of certain diagnoses between different NICUs and their accompanying standard treatment plans are, without adequate ways to disseminate this knowledge, an important barrier to providing the best possible care at the end of a neonate’s life.

“I think that getting an idea of how it is done in other hospitals is already a big thing. Because you don’t find out from each other how other hospitals do things. What their criteria are, for example, for stopping treatment in a child with severe periparturient asphyxia. With serious neurological abnormalities. I’d like just to be able to talk about that openly. Because everyone can get hold of the literature. But there is still a difference between reading a study and doing it for real in your department.” - Doctor 13

Legal framework

The current Belgian legislation was also mentioned by some neonatologists and nurses. When mentioned, they stated that the lack of a legal framework - actively ending the life of a neonate is currently not allowed - is seen as an important barrier in contrast to pregnancy, where there is the option to terminate as soon as a life-limiting foetal abnormality has been diagnosed.

“But, well, if the child hasn’t had any acute situations or complications yet, there’s nothing you can do. And those cases are rare, but they do exist. And then if you also have parents who are really asking urgent questions about ending things, well, there is actually nothing you can do as a doctor and I find that tough.” & “But something that concerns healthcare providers is the discrepancy in the legal situation between the prenatal and postnatal period. [...] This implies that prenatal, with lots of things that you can see and know, that you can also go quite a long way towards terminating the pregnancy and that there is probably an even bigger difference there than in what goes on neonatally?” - Doctor 10

Discussion

In this qualitative interview study with neonatologists and nurses working in a NICU we found factors that may hinder or facilitate end-of-life decision-making in neonates on three distinct levels, namely the case-specific context level, the decision-making process level and the overarching structure level. Key barriers and facilitators identified relate to specific characteristics of the involved actors (such as cultural and language differences, a therapeutic bond with parents and the experience of the healthcare practitioners), uncertainty of the prognosis, ACP and the influence of policy, legislation and medical practice.

Strengths and limitations

By using the qualitative approach of face-to-face interviews with both neonatologists and nurses we were able to give a view of what makes EoL decision-making in neonates easier or more difficult for them. We believe parents could have crucial additional insights which will be reflected on in a forthcoming separate publication; however the experience of bereaved parents fits less well into this study, whose focus is the theoretical generalizability of ELD experiences in neonates and how this can contribute to recommendations on the standard EoL decision-making process in neonates.

General discussion

Our results show there are some modifiable factors which may aid the complex end-of-life decision-making process, though some could be considered more possible to achieve than others.

The lack of privacy and separate rooms for bad-news conversations was mentioned by healthcare providers as a barrier to the EoL decision-making process. Creating privacy for bad-news conversations so that difficult ELDs can be made without unnecessary interference could aid both healthcare providers and parents, indicating that small changes could potentially have a large impact. There are similar findings in previous research into the paediatric intensive care unit, indicating that the intensive care unit is not seen as an ideal environment for EoL decision-making and broader EoL care since privacy cannot be assured(18).

Both neonatologists and nurses mentioned the importance of building into daily practice both multidisciplinary team meetings and debriefings after the death of a neonate. Previous research has already suggested making use of the collective wisdom of experienced healthcare providers to reduce uncertainty in a general intensive care setting(19). Especially in neonates, prognostic uncertainty is a key theme(20). Regular multidisciplinary meetings could provide healthcare providers with a higher degree of involvement within these ELDs and with a feeling of certainty that decisions are carried by the entire team, reducing unnecessary uncertainty.

Respondents emphasized the importance of ACP in neonates with a severe prognosis. Previous research already indicates the benefits of routine use of an individualized symptom management plan for neonates during EoL care(21). In adults, ACP is known to decrease decisional conflict for surrogate decision-makers, since they are more likely to know the patient's wishes(22). Also, in adolescents, ACP leads to better communication between adolescent, parents and healthcare providers(23). Aside from these possible effects of routinely implementing ACP in severely ill neonates, our results also indicate the facilitating effect of having previously planned courses of action for all possible outcomes on the EoL decision-making process for the healthcare practitioners involved.

Another significant factor includes promoting emotional support and a team-work culture amongst staff in a NICU. Making it possible to switch tasks during EoL care to relieve others so they can focus on the dying infant, or providing the opportunity for staff members to indicate whether or not they are willing to be part of an EoL decision-making process at that time, can have an influence on the overall wellbeing of healthcare practitioners themselves(24). Debriefings and evaluations to discuss emotional wellbeing of staff before, during or after an EoL decision-making process could further promote opportunities for them to support each other.

The need for more experience, and the need for more healthcare providers trained in neonatal EoL care mentioned by physicians and nurses can be linked together under a more general need for education and training in EoL care and ELDs. Previous research indicated that a high number of studies have reported a similar need for formal training in both bereavement care and overall EoL care communication skills, allowing time to learn from others(25). Including a module on neonatal death and EoL decision-making in standard curricula for healthcare practitioners increases clinical experience and EoL communication skills early on in training, which leads to enhanced confidence and fewer negative experiences with EoL care in the NICU(25).

Although parental involvement in EoL decision-making is currently common practice internationally(11), neonatologists and nurses indicated that when parents have a different cultural background to or speak a different language from the healthcare providers, difficulties in EoL decision-making may arise. Cultural differences can result in misunderstandings and/or fundamentally different views on the acceptability of certain ELDs. As in adults, we think that perinatal palliative care teams should be consulted to mediate as they are trained in difficult conversations(26). However, no current Belgian perinatal palliative care teams exist.

Some respondents mentioned the difficulty of the EoL decision-making process when severe future suffering is foreseen where withholding or withdrawing treatment would not result in the death of the neonate. This is because actively ending the life of a neonate is illegal within the Belgian legislation which therefore limits the possible options in such cases. Furthermore, previous studies indicate the occurrence of these active ELDs in Flanders(27) and the positive attitude of a high number of neonatal healthcare practitioners towards these types of ELDs(9). Our results can be the basis for an ethical and legal discussion about initiating legislation similar to that in the Netherlands where actively ending the life of a neonate is currently legislatively tolerated(28). Not having this option is currently seen as a barrier in difficult EoL decision-making processes. Because Belgium has both a euthanasia law in competent minors and adults, and a permissive law on late termination of pregnancy in case of severe or lethal fetal anomalies, we can state that Belgium has a permissive view on ethics concerning ending life. Possibly, these experienced barriers could be different in countries with a less permissive climate.

Finally, some of the influencing factors found in our study are not in the power of healthcare practitioners to modify, including the gestational age of the neonate, lower socio-economic or unfortunate household situations, and the effect on relating to a specific case because of similarities with their own situations. Being aware of these influencing factors during an EoL decision-making process in neonates can be seen as a crucial first step towards an easier decision-making process. Additionally, though participants did not indicate it themselves, training healthcare providers in ethical decision-making might aid in providing clarity when dealing with these complicated situations(29).

Conclusion

Our qualitative interview study revealed barriers and facilitators during the end-of-life decision-making process in neonates as reported by healthcare practitioners. Some modifiable factors were identified to improve the process, such as creating privacy for bad-news conversations, regular multidisciplinary meetings and debriefings to reduce uncertainty, routinely setting up an advance care plan, promoting emotional support and team-work culture amongst healthcare providers, a need for more experience in end-of-life care, a way to deal with cultural or language differences, and navigating a difficult legal framework; these possibly require more fundamental changes in NICU policy or overall society in order to facilitate the end-of-life decision process in clinical practice.

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Box 1: semi-structured interview guide

Question type	Question	Prompts
Introduction	I want to discuss the difficult topic of end-of-life decisions and would like to start with which decisions are sometimes being made in this NICU?	
Transition (only for nurses)	In what way are you, as a nurse, involved in taking these end-of-life decisions?	
Key	<ul style="list-style-type: none"> - What makes it easier for you to decide on end-of-life decisions? - What makes it more difficult to decide on end-of-life decisions? - Do you feel supported by colleagues or parents during this decision-making process? 	<p>We would like to focus on your own role as physician/nurse (and not on what makes it easier/more difficult for the parents).</p> <p>Other prompts include:</p> <ul style="list-style-type: none"> - Why does that make it easier/more difficult <i>for you</i>? - How did that make you feel? - Can you give a specific example of a case where this happened? And what decision was eventually made in this instance?

1 Table 1: demographic characteristics participants
2

	Neonatologists	Neonatal nurses
Number of interviewed caregivers	15	15
Staff in NICU...		
A	4	4
B	3	4
C	4	4
D	4	3
Sex		
Male	7	0
Female	8	15
Age		
< 30 years	0	3
30-39 years	7	5
40-49 years	6	4
> 50 years	2	3
Years of experience in a NICU		
< 5 years	2	5
5-10 years	5	1
11-20 years	4	3
> 20 years	4	6

1 Table 2: barriers and facilitators of the neonatal end-of-life decision-making
2 process

Theme	Description When the theme is only a barrier or a facilitator it will be indicated by a (b) or an (f). When the theme can be seen as a facilitator and the opposite can be seen as a barrier, only the facilitator or barrier is mentioned which will be indicated by (f; opposite = b) or (b; opposite = f)	Mentioned by...	
		Neonatologists	Nurses
Context	Characteristics of the specific case that influence the end-of-life decision-making process		
Child characteristics	- Medical diagnosis of the child:		
	⇒ Certainty of the diagnosis (f; opposite = b)	x	x
	⇒ A bad prognosis is quickly evident (f; opposite = b)	x	x
	- Baby is born at full term (b; opposite = f)	x	x
	- The infant looks healthy (b)	x	x
	- Medical options:		
	⇒ Every curative option was explored before considering an end-of-life decision (f)	x	
	⇒ Only possible end-of-life decision is actively ending the life of a neonate (b; opposite = f)	x	
Parent characteristics	- Cultural differences between parents and healthcare providers (b; opposite = f)	x	x
	- Different language (b; opposite = f)	x	x
	- Lower socio-economic status (f; opposite = b)	x	x
	- Having a therapeutic relationship with the parents (f; opposite = b)	x	x
Healthcare provider characteristics	- Experience		
	⇒ Experience with end-of-life decisions (f; opposite = b)	x	x
	⇒ Experience with disability and suffering of children later in life (f)		x
	- Personal characteristics		
	⇒ Having children of your own (b)	x	x
	⇒ Being/having been in a similar personal situation (b)	x	x
Process	Characteristics of the decision-making process itself		
Communication and (multidisciplinary) consultations	- Formal (organised) and informal (e.g. hallway encounter) communication:		
	⇒ Clear, efficient, and regular communication between parents and healthcare professionals (f; opposite = b)	x	x
	⇒ Healthcare professionals amongst themselves communicate clearly, efficiently and regularly (f; opposite = b)	x	x
	⇒ Formal debriefings after death to improve the end-of-life decision-making process in the future (f; opposite = b)	x	x
	- Formal and organised communication with (external) healthcare providers:		
	⇒ A second opinion about the diagnosis and/or the end-of-life decision (f)	x	
	⇒ Multidisciplinary meetings (f)	x	x
	⇒ Being included/consulted during the end-of-life decision-making process (f; opposite = b)	x	x
Divergence of opinion	- Between parents and healthcare providers (b; opposite = f)	x	x
	- Between healthcare professionals amongst themselves (b; opposite = f)	x	x
Advance care planning/ mapping of possible actions	- Planning the different possible outcomes and treatment options with healthcare providers and parents (f)	x	x
	- Healthcare providers know the norms, values and wishes of the parents (f; opposite = b)	x	x
	- Planning the dying process: Final moments are planned (who, how and when) and serene (f; opposite = barrier)	x	x
Structure	Characteristics of the overarching structure (society, NICU ward policy and practice)		
Emotional and practical support at the ward	- Emotional support from colleagues (f; opposite = b)	x	x
	- Support from a psychologist at the NICU is not available (b)	x	x
	- Culture in the NICU of colleagues working together, taking over tasks or assisting each other during the dying process of an infant (f)	x	x
NICU policy, practice and expertise	- Varying knowledge between the different NICUs (b)	x	
	- Not enough healthcare professionals trained in end-of-life care (b)	x	x
	- Absence of separate room to accommodate parents and infants during the decision-making process and before, during and after death (b)	x	x
	- Actively ending the life of a neonate with lethal drugs is not included in legal framework (b)	x	x
Legal framework	- Discrepancies between the legislation prenatally and postnatally (b)	x	

1 Appendix Table 1: COREQ (CONsolidated criteria for REporting Qualitative
 2 research) guidelines
 3

Topic	Item No.	Guide questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	5 (data collection)
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	5 (data collection)
Occupation	3	What was their occupation at the time of the study?	5 (data collection)
Gender	4	Was the researcher male or female?	5 (data collection)
Experience and training	5	What experience or training did the researcher have?	5 (data collection)
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	5 (recruitment & data collection)
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	5 (recruitment & data collection)
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	5 (recruitment & data collection)
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	5 (data analysis)
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	5 (recruitment)
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	5 (recruitment)
Sample size	12	How many participants were in the study?	5 (results)
Non-participation	13	How many people refused to participate or dropped out? Reasons?	N/A, participants gave their information when they wanted to participate. Healthcare providers without interest in participating were thus not contacted.
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	5 (recruitment)
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	5 (study design)
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	16 (table 1)
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	15 (box 1) and 5 (data collection)
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual	5 (data analysis)

		recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	N/A
Duration	21	What was the duration of the interviews or focus group?	5 (results)
Data saturation	22	Was data saturation discussed?	5 (data analysis)
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	N/A
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	5 (data analysis)
Description of the coding tree	25	Did authors provide a description of the coding tree?	17 (table 2)
Derivation of themes	26	Were themes identified in advance or derived from the data?	5 (data analysis)
Software	27	What software, if applicable, was used to manage the data?	5 (data analysis)
Participant checking	28	Did participants provide feedback on the findings?	N/A
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	5-10 (results)
Data and findings consistent	30	Was there consistency between the data presented and the findings?	5-10 (results)
Clarity of major themes	31	Were major themes clearly presented in the findings?	5-10 (results)
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	5-10 (results)

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